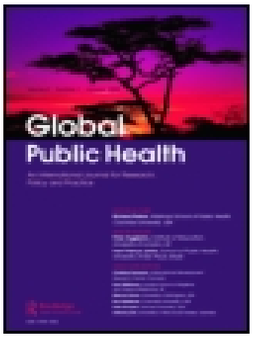

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Global Public Health

An International Journal for Research, Policy and Practice

ISSN: 1744-1692 (Print) 1744-1706 (Online) Journal homepage: https://www.tandfonline.com/loi/rgph20

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To cite this article: Ximena Salazar, Arón Núnez-Curto, Jana Villayzán Aguilar, Miluska Lusquiños, Angélica Motta Ochoa & Carlos F. Cáceres (2019): Confluent paths: Research and community participation to protect the right to health among transgender women in Peru, Global Public Health, DOI: 10.1080/17441692.2019.1599982

To link to this article: https://doi.org/10.1080/17441692.2019.1599982

Published online: 01 Apr 2019.

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GLOBAL PUBLIC HEALTH
https://doi.org/10.1080/17441692.2019.1599982

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Confluent paths: Research and community participation to protect the right to health among transgender women in Peru

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ABSTRACT
The recognition of transgender women (TGW) as the most vulnerable population to HIV/AIDS in Peru and their inclusion as a specific key affected population in health research was the outcome of an extended process that culminated when TGW community organisations succeeded in articulating themselves as a population separate from men who have sex with men (MSM) and, in alliance with some academic research groups, documented their HIV prevalence and vulnerability factors. Prior to that process, TGW remained subsumed under the epidemiological category of men who have sex with men (MSM), invisible in the context of public health policies. Based on a growing body of academic research evidence, coupled with the increasing number and capacities of TGW representatives in technical and policy-related gatherings, a consensus emerged for the establishment of TGW health statistics separate from MSM by 2010. During the past decade, social and health research has contributed conclusive evidence on the living conditions of TGW and the structural barriers they face, beyond the focus of HIV/AIDS research. Despite such progress, pervasive barriers in public policies continue to hinder the use of existing research evidence and community experience in the development of sensitive HIV prevention and care strategies as part of a comprehensive health model for TGW in Peru.

ARTICLE HISTORY
Received 24 October 2018
Accepted 21 March 2019

KEYWORDS
Transgender women (transwomen); HIV/AIDS; social movement; community organising; vulnerability; social health research

Introduction

Two decades ago a *transgender women's* (TGW) social movement did not yet exist in Peru. So called *travestis* (an emic term used mostly in the 90's) were considered by the public health sector and academia to be a small fraction of the male homosexual collective and one heavily marginalised (Salazar, Silva Santisteban, Villayzán, & Caceres, 2010; Silva-Santisteban et al., 2012). From 2006 onwards, Peruvian academic research has generated evidence that has allowed the recognition of TGW as one of the most HIV affected populations (Sánchez, Peinado, & Lama, 2011; Silva-Santisteban et al., 2012). These data have also highlighted barriers to TGW's gender affirmation, to access to health services, and to HIV treatment (Poteat et al., 2015), as well as other contextual factors this population experiences on a daily basis that heighten their HIV risk. Simultaneously, this scientific literature has produced broader insights with regard to the social reality of TGW, and TGW leaders and organisations have drawn on this evidence in becoming distinct actors in the field of HIV politics (Reisner et al., 2016), delineating confluent paths between trans activism and scientific research.

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In this way, the devastating impact of the AIDS epidemic did not render TGW immediately visible. Instead, we argue, it contributed to an ongoing process of transformation in the sexuality and gender landscape in Peru. This process began with the gay liberation movement in the 1980's and ended up providing the basis for claims, among a number of early TGW activists. With time, such activists articulated needs of the trans population that were fundamentally different from those of gay men and that required the constitution of a new movement, the transgender women's movement.

Globally, partnerships between LGBT organisations and academic partners are at present utilised as a vehicle to conduct community health interventions (Chillag et al., 2002; Griffith et al., 2010; Wilson, Lavis, & Guta, 2012). These partnerships have also been counted among the 'critical enablers' of combination HIV prevention programmes (Skovdal, Magutshwa-Zitha, Campbell, Nyamukapa, & Gregson, 2013). However, interactions among these partners are under-studied. Here we reflect on the relationship between the field of transgender health research and the strengthening of TGW organisations. This collaborative work cannot and need not be generalised to the entire local trans community and all academic institutions, but provides a basis for reflection on the processes of coalition formation between researchers and TGW organisations, which may bear political effects, despite their unresolved tensions. One example of these tensions is the ambiguous construction of the category transgender within academia evident in the persistence of gender dysphoria as a psychiatric disorder, while TGW are accepted as a legitimate community within the field of public health. Another issue is the instrumental use of TGW in HIV research, although, clearly, TGW activists who mediate the relationship between academics, funders and TGW organisations also have complex interests that play a role in these processes. Additionally, despite the wealth of health research that has been carried out so far, some concerns (violence, discrimination, civil and identity rights) expressed by TGW in diverse gatherings remain invisible and marginal in much research focused on HIV.

The goal of this paper is to explore the confluence of academic research and allies with processes of strengthening and consolidation of the TGW movement. We analyse the role of research and researchers in both building knowledge about and the enhancement of the TGW movement beyond HIV. Finally, while a full discussion of the role of funders and state parties in defining the TGW activist agenda is beyond the scope of this paper, we will briefly address their impact, as well.

Methods

We conducted an assessment that considered: (1) The evidence-base on TGW articulated in both peer-reviewed scientific papers and books and grey literature published in Peru between 2006 and 2011 (a period in which the most significant production of Peru-specific research on TGW took place). Importantly, many of these publications were authored by the first author of this paper along with other researchers of the Cayetano Heredia University. (2) This paper also benefits from the contribution of two TGW leaders, Jana Villayzan and Miluska Luzquiños, activists with long trajectories in social activism and co-authors of this article. Both are part of Red Trans Peru, an organisation that has been active from the start of a more articulated social trans movement. The first author of this paper has conducted research and has shared in meetings, discussions and activism with these leaders to address the problems of TGW in Peru.

Publications were tabulated to indicate authors, methodology and key findings. Grey reports were identified to help define milestones in the development of TGW activism. Data deemed useful in defining this history were identified and tabulated. Data sources and methods were triangulated to build understanding of the TGW movement in Peru, describe the contribution of research in such process, and identify the confluences and tensions between the roles and motives of both scientific and community actors. Quotes included in this paper come from the grey literature or from personal communications between the authors, involving Ms. Villayzan and Ms. Luzquiños (indicated as personal communications).

Findings

Research on TGW in Peru (2006–2011): A new population emerges in the field of health research

Health-related research on TGW in Peru began soon after 2000, with the first publications focused on TGW taking place around 2006. Table 1 lists key publications that engaged Peruvian TGW between 2006 and 2011. Most publications listed are focused on HIV, with some additional issues gaining attention as of 2008.

Approximately a decade before the emergence of the TGW population, this group remained subsumed within the overarching category of Men who have Sex with Men (MSM) in HIV/AIDS studies and global reports (Kaplan, Sevelius, & Ribeiro, 2016). As a concept that sought to describe homogenous sexual practices or sexual behaviours, the notion of 'biological sex' (as stable and homogenous) (Kaplan et al., 2016), together with the concept of sexual orientation, were seen as

Table 1. Methodological approach and key findings of scientific publications focused on TGW in Peru (2006–2011).

Authors/Year	Research method	Key findings/Conclusions
Salazar et al. (2006)	Qualitative	The study emphasises the importance of the socio-cultural environment for the prevention of HIV / AIDS by its influence on the social norms of gender in the construction of identity, in relationship forms, in sexual negotiation and in the meaning of risk.
Caceres et al. (2008)	Secondary information analysis	The study identifies that risk behaviours in the transvestite population are associated with adverse socio-economic and psychological conditions, contributing to the existence of a population highly vulnerable to HIV infection.
Salazar and Villayzán (2007)	Qualitative	One of the most important findings of this study was that prostitution in a transvestite population has as its indispensable condition the assumption of a female identity.
Montalvo, Andía, and Rodríguez, (2009)	Qualitative	The study proposes that violence against TGW comes with great force from public order institutions, such as the municipal and the national police.
Salazar and Villayzán (2009)	Qualitative	The study highlights TGW's efforts to achieve their desired identity in their bodies, and with family. The study also refers to the exercise of their human rights and few job opportunities, while a large number are engaged in prostitution.
Salazar (2009)	Qualitative	The study delineates the types of violence TGW suffer in several regions of the country
Salazar (2010)	Qualitative	The author argues that there are no laws, policies, norms and / or regulations regarding the social inclusion of TGW and that there are no capacity building mechanisms in trans organisations, which makes it difficult to participate in civil society forums.
Salazar et al. (2010)	Qualitative/ Quantitative	The study discusses the importance of institutions to recognising TGW identity. It highlights gender discrimination and violence as well as the difficulties experienced by women in their relationships with partners that influence condom use and HIV prevention. This is in addition to the problems TGW have in accessing health services.
Segura et al. (2010)	Quantitative	The study estimates 22,456 transgender women in the city of Lima
Bayer, Paca, and Garvich (2011)	Qualitative/ Quantitative	The study concludes that TGW sex workers experience greater vulnerability than TGW who are not engaged in sex work. Being sex work a factor of vulnerability. A significant minority has never been tested for HIV and therefore require specialised services to their needs.
Sánchez et al. (2011)	Quantitative/ Epidemiological	This study provides epidemiology of TGW in Lima, finding 20.8% HIV prevalence, 36.2% prevalence of syphilis. It argues that the HIV epidemic among MSM and transgender women is becoming increasingly young, with a higher incidence among the population under 25 years of age. This epidemiological data from a sentinel study is the data used by the Ministry of Health.
Silva-Santisteban et al. (2012)	Quantitative/ Epidemiological	This study developed with the Responding Driven Sampling methodology in the UPCH provides epidemiology of TGW in Lima, finding 29.6% HIV prevalence, 22% syphilis prevalence. It confirms that TGW represent the group most affected by the HIV / AIDS epidemic in Peru.
Velarde (2011)	Qualitative	The study concludes that the health system does not give attention to the need for body modification, nor for sexual health of TGW living with HIV

providing all relevant information for epidemiologic purposes. Even though several studies began to identify new populations at risk of contracting HIV (Caceres et al., 2008), for the calculation of prevalence, as well as for behavioural and qualitative studies, TGW were considered part of the MSM category. As of 2005, for the most part, international references to TGW still included them as part of the 'gay and other MSM' collective, as did the Peruvian Ministry of Health. Likewise, most local academic papers kept these groups together, although some started to distinguish a group of so-called 'MSM with female gender identity', or simply *travestis* (Salazar et al., 2006). During this period, the term 'vulnerable populations' was still being used, highlighting the structural determinants of HIV risk, beyond risks resulting from individual behaviours. In a study on alcohol and drug use published in 2007 (Caceres, Salazar, Rosasco, & Salazar, 2007), MSM and *travestis* appeared as separate groups. In this study, risk behaviours in the *travestis* population were closely associated with adverse psychological and social/structural conditions, resulting in their high vulnerability to HIV infection. At that point, interest emerged on the topic of sex work among TGW, known as one of the few economic activities available to *travestis*' livelihood (Salazar, 2009; Salazar & Villayzán, 2007; Salazar & Villayzán, 2009).

In 2010, a mixed methods study on TGW took place, focused on social and epidemiological dimensions of their vulnerability to HIV/AIDS (Salazar et al., 2010; Silva-Santisteban et al., 2012). The qualitative component of this study revealed, once again, the importance of the recognition of TGW and the need for their inclusion and legitimation. This study discussed how, in conditions of poverty and exclusion, TGW face health (including HIV-related) outcomes that cannot be isolated from other important experiences such as institutional violence, exclusion from the job market, poor housing conditions, and others. The quantitative study showed that TGW represented the group most affected by the HIV/AIDS epidemic in Peru, with an HIV prevalence of almost 30% (Silva-Santisteban et al., 2012).

Another publication focused on the STI and HIV Epidemiological Surveillance Study conducted in 2011 (Sánchez et al., 2011), raised concerns about the fact that the HIV epidemic among MSM and TGW was affecting increasingly younger people, with a higher incidence among populations under 25 years old. A study on HIV prevention and access to sexual and reproductive health services among people living with HIV carried out in eight Peruvian cities (Salazar et al., 2013) revealed that the TGW population had the lowest level of completed schooling in all geographical areas. With regard to experiences in health services, the majority of TGW was usually not offered information regarding the lack of interaction between hormonal treatment and the use of antiretroviral therapy (ART), so that fears about ART interfering with their feminisation process prevailed (Salazar et al., 2013).

Importantly, much of the qualitative research conducted (and even some mixed-methods efforts [Silva-Santisteban et al., 2012]) represented unintended examples of participatory research (PR), a paradigm in which activists work together with researchers and use the outcomes of research to improve living conditions of the TGW community (Currah & Spade, 2007). Such successful experiences have not only represented a learning experience for researchers and TGW activists alike; they have also demonstrated the critical role that research can play in advancing policy and advocacy work in the most vulnerable communities (Currah & Spade, 2007).

The development of the TGW's movement in Peru (2005–2011)

TGW organisations emerged less than 20 years ago in the context of the Peruvian LGBT movement. The first gay and lesbian organisations were founded in the early 80s (Bracamonte, 2011). During that decade, when the use of 'gender identity' as driving political mobilisation of gender non-conforming people had not started at a global scale, only a few TGW participated in actions promoted by gay groups in Peru (Jaime, 2013).

It is since the advent of the new millennium that TGW groups emerged, in the context of their participation in discussions for HIV/AIDS prevention organised by the Peruvian gay movement,

UNAIDS and the projects of The Global Fund to Fight AIDS, Tuberculosis and Malaria, and also in discussions of gender and sexuality within academic spaces. One of the first TGW organisations was Angel Azul, which appeared in 2002, growing from demands among some TGW for their own space in order to reflect on social aspects of their vulnerability beyond HIV risk. In those years, the term 'transgender women' was not well known among members of academia and the Ministry of Health, and TGW's specific needs (i.e. concerning social inequalities, such as lower access to health, non-availability of hormone therapy, human and sexual rights among others) was still an unexplored field.

In the specific case of Angel Azul, their contact during 2002 with Lohana Berkins, a brilliant trans activist from Argentina, helped them reflect on the structural drivers of their vulnerability to HIV, given that their non-conforming gender identification increased their social exclusion and stigmatisation, as compared to gay men, and they developed a new collective discourse on that basis. Another early group, 'Claveles Rojos', emerged out of the friendship among TGW coping with isolation and adversity in a hair salon in a poor district in Lima (La Mestiza Colectiva, 2008). These foundational groups focused their efforts on dealing with violence against TGW (Montalvo et al., 2009).

It was not until the year 2006 that the academic and political discussion about gender and sexuality influenced some TGW leaders, motivating their decision to strengthen their organisations. In 2006, Red Trans Peru started its activities as a national network of transgender women. This organisation led several activities aimed at creating a community, which now remain milestones of the TGW organisations' trajectory. As of 2007 meetings and activities that brought together TGW from all over the country and Latin America were organised in order to consolidate a coalition in Peru similar to those that had previously been formed in Argentina or Brazil. These milestones are summarised in Table 2.

Towards the second decade of the millennium, the TGW movement also started to receive support from international donors, who became conscious of their increasing visibility and demands, signaling the assumption of a political identity as the group most affected by HIV infection (Salazar et al., 2010). In those meetings, the concepts of 'transgender' (transgénero) and 'trans' (trans), originating in American academia and activism, began to be used to name body and gender experiences under a single term, and to articulate collective demands vis-à-vis international donors and the State.

The visibility of TGW as a vulnerable group and their participation in HIV interventions

During the last five years of the first decade of the new millennium, evidence produced by epidemiological and transgender health research, describing and explaining the high prevalence of HIV among TGW, played a significant role in articulating the demands of activism in this new context of convergence between organisations and the national HIV programme. This research provided, on the one hand, information to activists to support their demands for social recognition as distinct from 'MSM.' On the other hand, this scientific evidence was used to support their lobbying for self-representation before the Peruvian government.

HIV policies entered a stage characterised by technological sophistication and the establishment of specific goals in HIV prevention and treatment. Simultaneously, CONAMUSA – the name adopted in Peru by the Country Coordinating Mechanism (CCM) established to manage the activities related to the Global Fund to Fight AIDS, Tuberculosis and Malaria (GF) in Peru – promoted a

Table 2. Milestones of early transwomen activism in Peru (2005–2007).

Year	Milestones of early transwomen activism in Peru (2000–2007)
2005	First Transvestite, Transgender and Transsexual Encounter in Peru
2006	National Workshop on Stigma and Discrimination in the Transvestite, Transgender and Transgender Population
2006	Birth of the RedTrans Peru
2007	Regional Consultation on Sex Work and HIV/AIDS in Latin America and the Caribbean (in Lima)
2007	National Consultation on Sex Work, Human Rights and HIV and AIDS

distinct participation of TGW alongside other vulnerable communities introducing some capacity building activities among them (Jaime, 2013). These activities contributed to the visibility of the TGW population in Peru.

In this way, the HIV agenda not only became a field in which TGW's demands were articulated for social recognition; it also operated as a setting where technical and political capacity building for some TGW took place, resulting in strengthened political leadership. The technical capacity building took place in the areas of transgender health, project management, human rights training, and international networking. As a TGW leader noted in an interview for a 2010 report about the participation of transgender women in the Peruvian Global Fund Country Coordinating Mechanism (CCM):

> Regional networks of sex workers (RedTraSex) and trans (RedLacTrans) have played a crucial role in raising awareness among their members about the importance of getting involved in projects funded by the Global Fund. Moreover, they [the networks] have supported the local and regional advocacy work of their members to achieve representation at the CCM. (Salazar, 2010, p. 48)

However, TGW activists have also pointed out the tensions in the type of community participation facilitated by the GF. For example, they indicated that the GF's utilitarian (i.e. HIV-restrictive, funding-driven) view of participation left no room for other rights claims beyond HIV (Salazar, 2010); they also indicated that the assistance-focused project implemented by local NGOs created dependence among TGW rather than helping them develop capacities for self-maintenance.

> The Global Fund has created an assistance-focused project: We are supposed to expect to get support to rent a house, to be paid a space, to wait for the work of peer promoters (…). It has not contributed to strengthening the leadership of Trans people who stand in the regions and who have managed to get groups of twenty girls to follow them, perhaps supporting them to self-manage an organization. (Comment made by co-author Jana Villayzán during a training workshop funded by GIZ (German Cooperation) for Peruvian trans women, July 2016)

The trans movement and its ongoing struggle for comprehensive health

In Peru, the confluence between academic research and activism reveals that an overwhelming emphasis on HIV-focused public policy has not allowed for the recognition of other TGW's human rights needs and demands (Jaime, 2013). Currently the fundamental link between the health system and TGW in Peru remains HIV-focused, while in some other regional experiences, HIV services have been integrated with other TGW needs (Salazar et al., 2016).

On one hand the demand for comprehensive health has been expressed by TGW activists as a critical posture vis-à-vis the approaches of the Ministry of Health and clinical research: only HIV prevention and treatment are visible. As a TGW in a focus group noted in the same 2010 report about the participation of transgender women in the Peruvian CCM:

> We can also have other diseases, like stomach aches; we can get sick, we can have a migraine, in the hospital we look like 'guinea pigs' because they will only see you as if you have HIV … (Salazar et al., 2010, p. 19)

On the other hand, a claim that comes from transgender activists is the need to address structural problems identified by research in public policies which are intertwined with HIV (Bayer et al., 2011):

> I think that … I mean, I've always said, HIV is not only a health issue, it's a social issue, right? The [main] issue is different: they [the state and society] do not provide them [TGW] access to education, they do not let them work, they do not let them do thousands of things, they are being discriminated against, they are being hit from all sides, and they are being put far away. Their needs are still primary: food, housing, and love maybe. Doŕt you think so? (Comment made by co-author Miluska Lusquiños during an informal conversation about the demands of the trans population at a meeting in Bolivia, 2017)

Considering these claims, TGW's expectations toward health policies seek the integration and expansion of health services that can address TGW health needs and can tackle stigma, discrimination and social exclusion.

Discussion

After the long process described above, recently the exclusion of TGW from civil life has been problematised and addressed through some initial policy measures like the release of technical health standards for transgender women. During the early, most critical years of the HIV epidemic, they became visible, yet only as 'a group of high-risk MSM' who 'dressed as women' and were 'mostly involved in prostitution' (Segura et al., 2010). Twenty years later, the confluence between academic research and activism together with an international trend to make visible the situation of trans women in the world provided them with the opportunity to articulate a discourse that allowed TGW to emerge as a political group (and as a social actor) quite distinct from MSM, with their own culture and needs. In this paper, we have presented evidence of this process in Peru, of the role played by research conducted from a sexual rights/human rights perspective, and of the impact of collaboration between researchers and TGW organisations.

Health research focused on TGW in Peru has contributed to the constitution and consolidation of TGW organisations. Initially, such research fundamentally addressed biomedical/epidemiological concerns (i.e. HIV/sexually transmitted infections and associated 'risk factors') and operated mainly within a biomedical framework where the pathologizing view of non-conforming gender identity was accepted (Hausmann, 1995). Such a pathologizing view, we argue, led to TGW only being seen by policy makers, specialists in public health, international cooperation representatives and some academics through the lens of HIV. Over time, an increasing number of social science endeavours started to emerge. Initially, these were centred on HIV public policy (Ministerio de Salud del Perú, ONUSIDA, & Universidad Peruana Cayetano Heredia, 2014; Sánchez et al., 2011). However, a detour has been observed when social scientists started to work with TGW activists on at least two other themes: (a) human rights and structural vulnerability of TGW (Caceres et al., 2007; Salazar, 2009; Salazar et al., 2010, 2013; Salazar & Villayzán, 2009); and (b) sexuality, gender, and identity. Now, although the biomedical discourse and the discourse of human and sexual rights coexist, we have a more conscious and demanding TGW movement.

In our experience, working on human rights and structural vulnerability was not only useful from an advocacy perspective; it also helped depathologize TGW-focused research by both looking beyond disease and explaining the complex social determination of HIV risk. In turn, evidence produced by epidemiological and social research has been useful for TGW activists in their advocacy work, for example by using evidence to support their claim for recognition as a genuinely distinct constituency concerning the elaboration and oversight of GF projects (Salazar, 2010). Research evidence and academic discussion have also contributed to internal discussions about gender identity and organisational efforts as a TGW collective (Jaime, 2013; La Mestiza Colectiva, 2008). Finally, the demand among TGW for comprehensive transgender health research sheds light on the various social and subjective issues that still need to be addressed by research (Velarde, 2011).

Conclusion

The onset of the new millennium represented a period of change in the social response to HIV in Peru. In the context of: (a) changing international perspectives on sexuality, gender and diversity, and (b) an evolving response to HIV in Peru, with both TGW-focused research and activism-related components, the community of transgender women – previously assumed by researchers, public health decision makers and international HIV agencies to be a part of the MSM constituency – made the case for their independent participation in HIV policy and human rights discussions.

Research evidence initially reinforced the concept of TGW as the group most affected by HIV, without questioning pre-existing pathological views of TGW in the biomedical field, and possibly naturalising their HIV burden. Subsequently, and in light of the HIV burden they face, a wave of social science research, often undertaken in collaboration with TGW, produced new evidence that, by focusing on their vulnerability, human rights and additional health needs, directly

questioned the pathologizing paradigm and contributed to considerable growth of the TGW movement.

As we have shown, there are remaining issues that TGW activists are demanding should be seriously considered by government authorities, as well as by researchers. For example, body transformation procedures, transgender adolescence, transgender people's access to education, housing and employment, extreme poverty, internalised stigma among the community, social support, cohesiveness and community bonds – all are factors that influence TGW health outcomes, including HIV infection.

We firmly believe that by paying careful attention to TGW's social demands, and by assessing them with the participation of the community (as well as by reflecting on new ways to make that participation possible and ethical), research can contribute to resolving the substantial inequalities that continually repress TGW's quality of life.

Disclosure statement

No potential conflict of interest was reported by the authors.

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